

Chronic Kidney Disease Compendium

Educational Programs on Chronic Kidney Disease

Introduction

This section of the *Chronic Kidney Disease Compendium* includes information about programs dealing with various aspects of chronic kidney disease, including public, patient, and professional education programs and those in related areas. Programs that deal exclusively with end-stage renal disease are not included here.

The *Compendium* in its current form represents NKDEP's best effort to list available resources on chronic kidney disease; however the document is not exhaustive or comprehensive. Submission of appropriate entries is highly encouraged. Reference to the organizations, programs, and materials in this document are for informational purposes only and does not constitute or imply NKDEP's endorsement or guarantee of medical accuracy or completeness. Submissions should be sent via the comment section on the website http://www.nkdep.nih.gov/contact.htm or by mail to:

NKDEP

3 Kidney Information Way Bethesda, MD 20892-3575

Programs in this section are divided as follows: International Programs; U.S. Programs — National and Regional; U.S. Programs —Local. The index that follows is a guide to locating programs by subject area. Page numbers are provided for your convenience. You can use the "go to" page command in Adobe Acrobat to locate the item of your choice. For Mac users, press the Apple Key and N key together. For PC users, press the CRTL key and N key together. The index has the following subject headings:

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International Programs

Australia

Centre for Kidney Research Aboriginal Health Research Group and Menzies School of Health Research

P.O. Box 41096 Casuarina Northern Territory, 0811 AUSTRALIA http://www.kidney-research.org/projects.htm Dr. Wendy Hoy

Program Description: The Aboriginal Renal Disease Program, directed by Dr. Wendy Hoy, is based in a collaborative consortium between the Menzies School of Health Research in Darwin, NT, Australia, and the Center for Chronic Disease at the University of Queensland. Its research disciplines include: epidemiology, health services applications and health economics, sociologic gradients and health, clinical studies and morphologic studies and more basic molecular and genetic research. One important arm of this program is the Aboriginal Chronic Disease Outreach Program. This program aims to improve the awareness and management of chronic diseases (type 2 diabetes, hypertension, renal and cardiovascular diseases) in underserved remote Aboriginal communities. Resources include educational materials, protocols and algorithms for testing and treatment, training of health workers in these techniques and concepts, physician and specialist advice as needed, and a web-based database to record client data and permit ongoing analysis and reporting. This program is currently operating in three communities in the Northern Territory and in two Aboriginal Health Services in Western Australia. It is conducted by an organization called Kidney Disease Research and Prevention (KDRP), under contract to the Australian Kidney Foundation, and supported by funds from The Office of Aboriginal and Torres Strait Islander Health, Rio Tinto, Janssen Cilag and the Colonial Foundation of Australia. For more information, please contact Ms. Jo Sheppingen at jo@kdrp.org

Brazil

Dialogo®

Catholic University of Parana Curitiba BRAZIL Miguel C.Riella, MD, PhD, FACP, Professor of Medicine

Program Description: Pro-Renal Foundation has developed a Chronic Kidney Disease Education Program, "Dialogo®" based on a series of lectures:

- Major causes of ESRD (end-stage renal disease)
- Progression of CRF (chronic renal failure)

- When to refer a patient
- What the nephrologist will do
- Role of nutrition

The program is a 3-hour module designed for the local health care systems. Cities in Brazil are divided into "sanitary districts." For instance, Curitiba has 8 districts with about 200,000 people per district. Each district has about 20 ambulatory facilities with one providing 24-hour coverage. Each facility has a general practitioner, pediatrician, and obstetrician-gynecologist. All physicians are gathered at one of the facilities and conduct the module. Each participant receives a certificate of attendance and an educational manual. More importantly, they are provided with addresses, emails, and telephone numbers of nephrologists to whom they can talk or refer their patients. This program has been used in Curitiba and may be extended to other parts of the country.

CRI Census

Head, Nephrology Division Federal University of Juiz de Fora BRAZIL

Email: marcusgb@nutecnet.com.br

Marcus G. Bastos, MD

Program Description: Currently outlining a project to our local health authorities to perform a census of chronic renal insufficiency (CRI) within our community.

Canada

Staying Healthy with Bad Kidneys

All talks are available online at the Doc-To-Me Website: http://www.hdcn.com/doctome/symp/00dtm/dtm2000.htm

Program Description: "Staying Healthy with Bad Kidneys" conference in Toronto in October 2000, after an Association Society of Nephrology meeting. There were eight speakers talking to a patient audience brought together by Dr. David Mendelssohn. The agenda included:

- Introductory remarks—John T. Daugirdas, MD
- How can I stay off dialysis?—David Mendelssohn, MD
- I have diabetes. How can I protect my kidneys?—Eli Friedman, MD
- What kinds of food should I eat and stay away from?—Adrian Fine, MD
- How do I protect my bones when I have kidney disease?—Jill Lindberg, MD
- What about my blood count? How can I keep this up?—Adeera Levin, MD
- Which form of dialysis is right for me?—Peter Blake, MD
- What do I need to know about my blood pressure?—Robert D. Toto, MD
- Is transplantation the right option for me?—Thomas G. Peters, MD

Also available on HDCN (Hypertension, Dialysis, and Clinical Nephrology, http://www.hdcn.com) is a series of lectures given to patients put together by Ron Hogg dealing with (a) Proteinuria (6 talks); (b) IGAN (IgA nephrology) (6 talks); and (c) HUS (hemolytic uremic syndrome) (6 talks). Two talks each year have also been presented dealing with polycystic kidney disease.

Singapore

National Kidney Foundation, Singapore

81 Kim Keat Road Singapore 328836

Email: service quality@nkfs.org

Website: http://www.nkfs.org/visitor_centre/our_services/preventive_Programme.html

Program Description: The National Kidney Foundation of Singapore's (NKFS's) first goal was to educate the public about end-stage renal disease (ESRD) options. An early success was the passage of the Human Organs Transplant Act that presumes consent for organ transplantation unless the individual had objected to it during his or her lifetime. The number of transplants has increased.

In Singapore, all dialysis is financed by personal funds, so most patients (95 percent) who needed dialysis were dying. In 1987, NKFS introduced a program to subsidize renal replacement therapy.

The population in Singapore presented a unique opportunity for a public health education campaign because of the increasing incidence of ESRD and the high prevalence of diabetes in this island nation

United Kingdom

The National Kidney Research Fund

Registered Office Kings Chambers Priestgate Peterborough PE1 1FG

ENGLAND

Tel: +44 (0) 1733 704650 Email: enquiries@nkrf.org.uk Website: http://www.nkrf.org.uk **Program Description:** The National Kidney Research Fund (NKRF) in the United Kingdom (UK) has started a screening and at-risk assessment program that is focused on its major ethnic communities, namely Indo-Asian and African Caribbean. The program started in September 2000 when NKRF established an advisory group, bringing together nephrologists and members of other relevant groups including the Department of Health, political lobbyists, Diabetes UK, social scientists, the Asian business community and patient representatives. The initial plan had been a brief awareness campaign but it was argued that much more was needed, particularly with regard to informing primary care physicians and others.

NKRF has now established an awareness and community education campaign, entitled "A Better Life through Education and Empowerment" (ABLE). ABLE includes the following components:

- Commissioning a position paper on the subject (in draft).
- Successfully getting "pump priming" funds from the Department of Health for an initial awareness campaign.
- Applying for further funding—establishing links with other funding bodies and drug companies.
- Launched a program with a presentation of the paper at the House of Commons on 5th December 2001 and a week of screening in Brent in London. (see http://www.nkrf.org.uk/pages/news/ABLEbackground.htm). There is also a much longer term community program being developed that will pilot in Leicester but then roll out into five other areas with large ethnic communities. The key individuals involved at NKRF are Professor David Kerr, Lesley Woolnough who is the project manager of ABLE at NKRF, and Penny Owen who is the lead fund raiser for this project.
- Raising awareness of the need for education, implementation of best practices, and the need for new research into causes. The timing is important, as the British Government has recently launched a program to develop a "National Service Framework" (NSF) for renal medicine. This will be a hugely influential strategic plan that will shape the future of renal provision in the UK. An entire module targets issues of prevention and slowing progression. The NSF is written by civil servants/ministers who are informed by the External Ref Group (ERG).

Dr. Robin Jeffrey, a nephrologist from Bradford, and Gurch Rhandawa, a social scientist, attended the Santa Fe satellite meeting on Renal Disease in Racial and Ethnic Minority groups and presented a report on the meeting to the ERG in December. All being well, this will focus the NSF on the importance of targeting these high-risk groups, particularly in light of the difficulties they face once on dialysis with respect to waiting for transplants. One of the aims of the civil servants involved is to establish links with experts in other countries who are addressing the same issues. They have highlighted the United States as key since the proportion of individuals dialysed is so much higher in the U.S. and also since type 2 diabetes is even more prevalent.

• Finally, the newly revamped UK transplant authority (UKT) is also acutely aware of the issues facing ethnic patients on dialysis. In the UK, kidneys are allocated on best match, and because there are so few donors from ethnic communities, ethnic patients wait much longer. The issues are complex and include lack of access to ITU as well as cultural beliefs.

U.S. Programs

National and Regional

The African American Study of Kidney Disease and Hypertension

National Institute of Diabetes and Digestive and Kidney Diseases National Institutes of Health Building 31, room 9A04 31 Center Drive, MSC2560 Bethesda, MD 20892-2560 Lawrence Agodoa, MD, NIH Director of AASK

The African American Study of Kidney Disease and Hypertension (AASK) is funded by the National Institute of Diabetes and Digestive and Kidney Diseases and the National Center on Minority Health and Health Disparities.

The study found that the angiotensin-converting enzyme (ACE) inhibitor ramipril slowed kidney disease by 36 percent and slashed the risk of kidney failure and death by 48 percent in patients who had at least a gram of protein in the urine. The drug was compared to the dihydropyridine calcium channel blocker (CCB) amlodipine. Results were not related to blood pressure control, which was comparable between study groups.

ACE inhibitors have been the preferred treatment for kidney disease of diabetes since 1994, and now AASK doctors are recommending it for kidney disease of hypertension, especially for people who also have protein in the urine. While CCBs help many patients, particularly African Americans, control blood pressure and reduce the risk of stroke and heart disease, patients may need an ACE inhibitor to protect the kidneys.

AASK stopped using the CCB as a mainline treatment in September 2000 on the advice of a data and safety monitoring board. AASK investigators continued to compare the ACE inhibitor and the beta blocker metoprolol and two blood pressure goals until the fall of 2001, when the study ended. Follow-up studies are now being planned.

African Americans make up 13.9 percent of the U.S. population but 29.8 percent of people treated for kidney failure. Hardest hit are blacks ages 25 to 44, who are 20 times more vulnerable to hypertensive kidney failure. Better management of high blood pressure has led to fewer strokes and heart disease, but kidney failure is increasing. In 1998, nearly 398,000 people were treated for kidney failure in the United States, costing an average \$43,000 per person for a total of \$16.7 billion.

A list of participating centers is available at http://www.niddk.nih.gov/welcome/releases/10-13-00.htm

American Association of Kidney Patients (AAKP)

3505 East Frontage Road, Suite 315

Tampa, FL 33607

Phone: (800) 749-2257 or (813) 636-8100

Fax: (813) 636-8122 Email: <u>info@aakp.org</u>

Website: http://www.aakp.org

Program Descriptions: The **Kidney Options** program was developed by Fresenius Medical Care, North America, in association with the American Association of Kidney Patients (AAKP). This educational program was designed to be a comprehensive resource for patients who are at risk for kidney disease or have recently been diagnosed and for their families and friends. Kidney Options uses seminars, videos, a website at http://www.kidneyoptions.com and other educational materials to emphasize the importance of patients learning about kidney disease—its causes, symptoms, and available treatment options. Telephone: (866) KIDNEY1 (543-6391).

Stay in Touch, A Kidney Education Program was developed by Baxter Healthcare Corporation in collaboration with AAKP. This integrated education initiative is for people at risk for or diagnosed with chronic kidney disease. The purpose of the program is to help people achieve health and wellness as they learn to live with kidney disease. The program helps people learn about causes, symptoms, and treatments for kidney disease. It consists of a series of informative educational mailings sent directly to a person's home. In some areas, group classes and individual consulting services with a Baxter Kidney Patient Educator are available. Website: http://www.kidneydirections.com Telephone: (877) 543-6394.

American Kidney Fund

6110 Executive Boulevard, Suite 1010

Rockville, MD 20852

Phone: (800) 638-8299 or (301) 881-3052

Fax: (301) 881-0898

Website: http://www.akfinc.org

Phylis Ermann

Program Description: The American Kidney Fund has an outreach program targeting African Americans at risk for kidney disease in Baltimore/Washington, Atlanta, Chicago, and Los Angeles. It has the following three components:

- Church health fairs: Work with health ministry to provide free medical screening tests (glucose, blood pressure, urine dipstick, blood chemistry), healthy snacks, and follow-up with a physician. They are collecting data on the success of this program.
- Community health fairs: Blood pressure and glucose screening and distribution of information.

• **Family fairs**: In dialysis units for families of existing dialysis patients. Offers screening and information for family members and an educational program for dialysis patients.

American Nephrology Nurses Association (ANNA)

ANNA National Office East Holly Avenue Box 56 Pitman NJ 08071-0056

Phone: (888) 600-2662 or (856) 256-2320

Fax: (856) 589-7463 Email: <u>anna@ajj.com</u>

Website: http://anna.inurse.com

Program Description: American Nephrology Nurses Association Pre-ESRD Conference: Discussion of questions and problems that arise in patients with early renal insufficiency or patients who are pre-end-stage renal disease (ESRD). ANNA members can share concerns with other members who are caring for the same patient populations.

Indian Health Service Kidney Disease Program

801 Vassar Drive, NE Albuquerque, NM 87106 Phone: (505) 248-4018 Fax: (505) 248-7698

Email: <u>anarva@abq.ihs.gov</u> Andrew S. Narva, MD, FACP

The Indian Health Service (IHS) Kidney Disease Program provides assistance to tribes in kidney disease surveillance, intervention, training, and research. The direct care component of the Kidney Disease Program has been implemented in New Mexico where 9 percent of the State population and 33 percent of the end-stage renal disease (ESRD) population is American Indian. The IHS Kidney Program in New Mexico is a model for providing care to patients with progressive renal disease and ESRD in a rural setting where most care is provided by primary care physicians and access to specialized care is a significant problem. It incorporates approaches to care advanced by the Kidney Disease Outcomes Quality Initiative (K/DOQI) including a team approach to the kidney patient beginning at the early stages of renal injury. Standards of care have been disseminated to primary care providers. Patients seen at IHS hospitals and clinics may be referred to Renal Clinic at any time in the course of their disease. Primary physicians are encouraged to refer early to assure optimal conservative therapy. Ongoing care to these patients is subsequently a collaboration between the nephrologist and the primary physician. Frequency of Renal Clinic visits is determined only by clinical need. Patients with progressive disease are introduced to the idea of ESRD and modalities of renal replacement therapy early to allow maximum time for education and emotional adjustment. IHS nutritionists from throughout the country have been trained in implementing diets to conserve renal function. Additional training has been conducted for clinic nurses, inpatient nurses, physicians, health educators, and field health workers to serve as the rural "eyes and ears" of urban dialysis and transplant centers.

Life Options Rehabilitation Program: Kidney School™

Life Options Rehabilitation Program c/o The Medical Education Institute 414 D'Onofrio Drive, Suite 200

Madison, WI 53719

Phone: (800) 468-7777 or (608) 833-8033

Fax: (608) 833-8366

Email: Lifeoptions@MEIresearch.org

Website: http://www.lifeoptions.org or http://www.kidneyschool.org

Program Description: The Life Options Rehabilitation Program, supported by Amgen Renal Advances, is dedicated to helping people with kidney disease to live long and to live well.

Kidney SchoolTM is a web-based, interactive learning center in sixteen 20-minute modules.

Based on 9 years of Life Options research with thousands of kidney patients, Kidney School is designed to help people with chronic kidney disease learn to take on a self-management role in their care that will help them improve their own safety and survival. Available for free, 24 hours a day, Kidney School allows interested users to choose the information they want to learn. Each module has a pretest and posttest, patient quotes, graphics, and photos, and will create a Personal Action Plan that summarizes the content and patient's questions and concerns.

National Kidney Disease Education Program (NKDEP)

National Institute of Diabetes and Digestive and Kidney Diseases National Institutes of Health 3 Kidney Information Way Bethesda, MD 20892

Website: http://www.nkdep.nih.gov

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health has recently initiated the National Kidney Diseases Education Program (NKDEP). This program will raise awareness about the seriousness of kidney disease and the importance of prevention, early diagnosis, and appropriate management of the disease and its complications.

The program will target primary care providers and people at high risk for kidney disease, particularly those with diabetes, hypertension, and/or a family history of kidney failure. In its first phase, NKDEP will conduct educational campaigns for at-risk African Americans and health care providers in four pilot sites. Messages will focus on identifying risk factors for kidney disease, screening those at risk, and providing appropriate treatment for those who are diagnosed with kidney disease. The four pilot sites are Baltimore, Maryland; Atlanta, Georgia; Jackson, Mississippi; and Cleveland, Ohio. These sites will enable the program to identify successful strategies to launch a broader national campaign. In its next phase, NKDEP will broaden its reach to American Indians and Hispanic/Latinos.

Other program activities include creating a compendium of existing educational programs and resources on chronic kidney disease; developing clinical tools for primary care providers;

improving laboratory reporting of kidney function; and developing an evaluation plan to assess the program's impact on the target audiences at the pilot sites as well as the long-term impact of the overall program.

National Kidney Foundation

30 East 33rd Street, Suite 1100 New York, NY 10016

Phone: (800) 622-9010 or (212) 889-2210

Fax: (212) 689-9261 Email: info@kidney.org

Website: http://www.kidney.org

Program Descriptions: The following section describes several of the National Kidney Foundation's (NKF's) educational programs about chronic kidney disease.

Kidney Early Evaluation Program (KEEP), NKF's early evaluation and screening program, is designed to identify those at increased risk for kidney disease, for people who are 18 years old or older and have high blood pressure or diabetes, or have a family member with high blood pressure, diabetes, or chronic kidney failure. Through a comprehensive evaluation process consisting of five screening stations: (1) Registration; (2) Blood Pressure and Weight Measurements; (3) Screening Questionnaire; (4) Lab Portion (blood and urine specimen collection); and (5) Consultation with Physician, the KEEP program will help to identify risk for kidney disease. The NKF conducts follow-up with those individuals whose test values are outside the normal range. KEEP participants whose test values are abnormal are advised to seek further evaluation from a physician. Those who do not have access to medical care are referred to a health care provider. All KEEP participants are sent their entire screening results within a few weeks after the screening. Approximately 2 months after the results are sent, participants deemed at risk are contacted via mail or telephone to determine if they consulted a physician.

With the introduction of the Kidney Disease Outcomes Quality Initiative (K/DOQI) Chronic Kidney Disease guidelines, another exciting component soon to be added to KEEP 2.0, will be the addition of the participant's physician to the follow-up. In addition to educating the participants, the participant's physician will also receive treatment and management recommendations from the NKF. These recommendations will be based on clinical practice guidelines and the scientific evidence available. By providing this information to the participant's physician, the NKF's goal is to have an impact on the quality of care patients receive and their outcomes. Currently 32 NKF affiliates offer the KEEP program in their communities. Information about the program is available at http://www.keeponline.org.

Additionally, NKF is planning an expanded version of KEEP, KEEP 3.0, which is a cohort study to evaluate and monitor at-risk individuals for a period of 2 to 3 years. It will be conducted at 15 clinical sites across the country and is scheduled to launch in the last quarter of 2002.

Below is a list of NKF affiliates who offer KEEP:

- 1. Arizona Kidney Foundation
- 2. NKF of N. California
- 3. NKF of S. California
- 4. NKF of Connecticut
- 5. NKF of Delaware
- 6. NKF of Florida
- 7. NKF of Georgia
- 8. NKF of Hawaii
- 9. NKF of Illinois
- 10. NKF of Indiana
- 11. NKF of Iowa
- 12. NKF of Kentucky
- 13. NKF of Louisiana
- 14. NKF of Maine
- 15. NKF of MA/RI/NH/VT
- 16. NKF of Michigan
- 17. NKF of Minnesota
- 18. NKF of E. Missouri & Metro East
- 19. NKF of Nebraska
- 20. NKF of Central NY
- 21. NKF of of Northeast NY
- 22. NKF of Upstate NY
- 23. NKF of Western NY
- 24. NKF of N. Carolina
- 25. NKF of Oklahoma
- 26. NKF of S. Carolina
- 27. NKF of E. Tennessee
- 28. NKF of Middle Tennessee
- 29. NKF of W. Tennessee
- 30. NKF of South & Central Texas
- 31. NKF of West Texas
- 32. NKF of Utah
- 33. NKF of Virginia

The contact information for NKF affiliates may be found at http://www.kidney.org/general/affiliates/nkf_affiliates.cfm.

"People Like Us," the seven-part video series that targets the newly diagnosed individual with chronic kidney disease, is available in both Spanish and English. This comprehensive program includes seven videotapes, seven sets of patient booklets, three leader's guides, and a patient record chart. Individual components are as follows: An Overview; Hemodialysis: Choosing a Treatment That's Right for You; Peritoneal Dialysis: Choosing a Treatment That's Right for You; Transplantation: Choosing a Treatment That's Right for You; Good Nutrition: Eating Right; Coping: Managing Your Kidney Disease; and EPO: Treating Anemia.

People Like Us, Live! (http://www.kidney.org/patients/live.cfm) is an interactive patient education program that openly addresses many fears and concerns that patients and family members face when diagnosed with chronic kidney disease. The program provides the objective, unbiased factual information they need in order to make informed lifestyle and treatment choices. This program encourages these individuals and their family members to take an active part in making decisions that will affect their overall quality of life and gives them hope. In six segments, the program content addresses coping and lifestyle issues, nutrition, and the various treatment options. Experienced professionals in the field of kidney disease, as well as patient and family presenters, teach all classes.

NKF's K/DOQI Learning System, or KLS, a new NKF initiative, is an educational matrix that encompasses all NKF programming for public education, patient services, and professional education. The entire continuum of chronic kidney disease (CKD), including all five CKD stages (Stage 1: Kidney damage with normal kidney function; Stage 2: Kidney damage with mild decrease in kidney function; Stage 3: Moderate decrease in kidney function; Stage 4: Severe decrease in kidney function; Stage 5: Kidney failure) and those "at increased risk" for developing CKD will be addressed in KLS programming. The public education arm of KLS will include programs to increase public awareness about chronic kidney disease and target those at "increased risk" for CKD. The KLS arm for patient and family programming will comprise education for all individuals affected by CKD at any stage across its continuum. The professional education arm of KLS will include comprehensive, multidisciplinary programming for all health care professionals in all specialties—physicians, dietitians, social workers, nurses, and technicians—and will address professional and continuing education needs in relation to CKD. K/DOQI will serve as the scientific foundation for all program content. KLS will include the following components:

- **Mat Releases.** A camera-ready article will be distributed to 10,000 newspapers in 2002. The article will offer NKF's Risk Factor and Urinalysis brochures and provide the NKF website and toll-free number for additional information. Primary users are suburban papers with circulation under 25,000; mats are also used by major dailies.
- **Public Service Ad TV.** A public service ad, featuring basketball star Alonzo Mourning, talks about the importance of routine urinalysis and early detection. Information about urine and blood testing and blood pressure measurement, and their importance in early detection, is emphasized.
- **Poster.** Three posters featuring Sean Elliot and Alonzo Mourning offer information about the primary causes of kidney disease. The posters also give information about urine and blood testing and blood pressure measurement, and their importance in the early detection of kidney disease. The NKF's toll-free number and website are provided for more information.

NephCure Foundation

505 East Huron Street, Suite 302

Ann Arbor MI 48104 Phone: (866) 637-4287

Websitet: http://www.nephcure.org/index.html

Program Description: The NephCure Foundation provides several programs for the benefit of patients and their families. The NephCure Network is a way of bringing together those who need support in dealing with glomerular diseases and those who wish to give that support. There are six components to the NephCure Network: the mentoring program, which matches newly diagnosed patients and parents to others for support and encouragement; a contact list of those who will provide a listening ear in a hotline format; the Tool Kit, which will give opportunities to those interested in providing support and fundraising for the Foundation; Psychologist Web Casts, a question/answer forum with a psychologist specializing in chronic health issues; a web-based support listserv for patients and families; and a list of links.

Other resources include a toll-free support telephone number, which will forward to a 24-hour pager, and educational materials for patients. Because of the disproportionate number of persons of color afflicted by glomerular diseases, services will be designed to target those communities. Outreach will be provided to ensure that the communities understand the effects of and ways to prevent glomerular diseases. Targets will include church groups, community centers, senior centers, groups such as the NAACP and the National Council of LaRaza, and legislators whose constituents can most benefit from this information.

RMS Disease Management (RMS), Inc., Baxter Healthcare Corporation

1620 Waukegan Road – A2S McGaw Park, IL 60080 Phone: (877) 767-3141

Fax: (847) 473-6114

Website: http://www.rmshealthsystems.com

Program Description: RMS Disease Management, Inc., is a disease management program coordinator for people with chronic kidney disease (CKD) and end-stage renal disease (ESRD). The program for CKD patients who are not yet on dialysis has medical management guidelines that stratify the patients into an appropriate CKD stage, depending on the level of kidney function. The most exciting opportunity in the long term is to reduce the incidence and prevalence of ESRD through aggressive population management of those CKD patients in the early stages. Since diabetes, hypertension, and cardiac disease are primary precursors of progressive renal disease, RMS proposes integration with those programs already in place to reduce the cost and delay the progression of CKD to ESRD. With trained nurses coordinating patient care, the education and tracking that CKD patients require can be provided. Most CKD patients have three to four co-morbidities by the time the CKD is detected, and these are difficult to manage. Combining an ESRD and CKD program through nephrology leadership, with the use of clinical guidelines, allows for a seamless program of patient management.

The company uses a nurse-driven model with nephrology leadership. The nurses are called Health Service Coordinators (HSC). HSCs have a tremendous amount of ESRD experience and are trained to handle 80 to 100 ESRD patients and 250 patients with renal insufficiency. The medical management process is managed with software designed for this purpose. The HSC does an initial patient assessment in the patient's home, develops a care plan with the nephrologist that addresses individual patient needs, implements the care plan (patient education with an agenda for each patient to take to their doctor based on guidelines of care and the assessment process), collects outcome data, and meets with the doctors and health plan coordinators on a quarterly basis.

The program is guideline driven and is based on three stages of renal insufficiency and four areas of care—physical and emotional assessment, laboratory results, self-management, and the necessary interventions at each stage. The emphasis is on early detection to identify and minimize the co-morbidity of diabetes, hypertension, anemia, and cardiovascular disease; prepare for renal replacement therapy (early referral, the modality choice, access prior to initiation of dialysis); and retard progression of kidney disease. RMS will be tracking this population to demonstrate a change in the progression of kidney disease.

The primary care physicians (PCP) continue to monitor these patients with the help of the HSC and receive an outline of support from the nephrologist once or twice a year in stages 1 and 2, respectively. In stage 3, the PCPs agree that the care is too complex and belongs in the hands of the nephrologists. The patients benefit from the interpersonal contact with the HSC and the HSC acts as an advocate for the patient and the family. The nurses are expected to sit down to a meal with the family once every couple of months.

Local Programs

A number of National Kidney Foundation affiliates run the Kidney Early Evaluation Program (KEEP). Participation is noted by **KEEP** under the affiliate listing; please see the National Kidney Foundation entry on page 13 under National Programs for a description of the program.

Arkansas

National Kidney Foundation of Arkansas

#1 Lile Court, Suite 201 Little Rock, AR 72205 Phone: (501) 664-4343 Fax: (501) 664-7145

Email: nkfa@aristotle.net

Website: http://www.kidneyar.com
Heather Powell, Program Director
Robert Glass, Development Director

The National Kidney Foundation of Arkansas has a Minority Health Committee that goes out into the community and does health fairs and screenings. They provide literature on the kidneys, warning signs of kidney disease, high blood pressure, etc. The committee members follow up with those found to have high blood pressure and encourage them to see their doctor or offer them information on free clinics in their area.

California

National Kidney Foundation of Northern California

Phone: (650) 349-5111 Fax: (650) 349-5115

Email: mbekiri@earthlink.net
Website: http://www.kidneynca.org
Janet Rose, Executive Director
Melanie Bekiri, Program Director

Programs include:

- **KEEP** (Kidney Early Evaluation Program)
- Health Fairs
- **Healthy Kidneys for Life**: Similar to the Kidneys in the Classroom program, Healthy Kidneys for Life targets fifth-grade children with ethnic minority backgrounds to teach them about healthy lifestyles to prevent kidney disease. Each student is screened for high blood pressure. Those students with elevated pressures receive a "High Blood Pressure Packet" and a voucher to pay for a follow-up visit if they do not have medical insurance.

• "Taking Charge: A guide to managing your kidney disease": This original booklet helps patients navigate through the many appointments they face when diagnosed with kidney disease. It provides questions to ask of the health care team, a medication log, a blood test log, and resources for further information.

Connecticut

The National Kidney Foundation of Connecticut

920 Farmington Avenue West Hartford, CT 06107 Phone: (860) 232-6054 Fax: (860) 236-1367 Email: info@kidneyct.org

Website: http://www.kidneyct.org

Marcia Hilditch

The Kidney Foundation of Connecticut has a strong minority outreach program. Each year the Connecticut Minority Outreach Committee (MOC) welcomes community leaders to a reception during Black History Month (February). In addition, the MOC offers educational seminars twice a year to educate church and community groups about the high incidence of kidney disease among Latinos and African Americans. Preventive screenings are also available. New programs are being developed to educate those who seek health care at urban community health care centers and emergency rooms.

Other prevention/education programs include:

- **KEEP** (Kidney Early Evaluation Program)
- **Speaker's Bureau**: Volunteers are available to address corporations, clubs and organizations and other groups about kidney disease, urinary health, and/or organ donation and transplantation.
- **Health Fairs**: Volunteers staff more than 65 health fairs around Connecticut each year. Information concerning the prevention and treatment of kidney disease is available, as well as organ donor cards and information.

Georgia

The National Kidney Foundation of Georgia

2951 Flowers Road South, Suite 221

Atlanta GA 30341 Phone: (800) 233-6339

Website: http://www.nkfg.org

Chris Starr, Director

Judy Bellinger, Head of Program

The National Kidney Foundation (NKF) of Georgia has initiated a Statewide education and prevention program called KEEP (Kidney Early Evaluation Program) run out of the Atlanta offices. They are currently beginning a capital campaign to raise enough endowment to ensure its perpetuity without having to depend on annual drives. The Program Director at the NKF of Georgia is an African-American transplant recipient who spoke and exhibited at a conference of the NAACP. The affiliate gave presentations at churches, senior centers, and Lions Clubs and celebrated at an African-American church the birthday of a member's transplant. The community came to the affiliate because of the message and asked to hear more.

Kansas

The National Kidney Foundation of Kansas and Western Missouri

1900 West 47th Place, Suite 310

Westwood KS 66205

Phone: (800) 444-8113 or (913) 262-1551

Fax: (913) 722-4841

Website: http://www.kidneyksmo.org/interprevention.htm

The National Kidney Foundation of Kansas and Western Missouri offers a nationally recognized Early Intervention and Prevention Program designed to: (1) identify those at risk for kidney disease; (2) encourage follow-up with a participant's own primary physician for further evaluation and treatment options; and (3) empower individuals through education and awareness of their ability to prevent or delay kidney disease. To date, more than 2,000 people have participated in the program, which is conducted in collaboration with dialysis units, corporate worksites, churches, health fairs, and clinics. Of these, 62 percent have required follow-up due to abnormal results.

Louisiana

The Ochsner Clinic Foundation

1514 Jefferson Highway New Orleans, LA 70121

Phone: (800) 874-8984 or (800) 348-7876

Website: http://www.ochsner.org

The Ochsner Clinic Foundation offers an early education and training program for pre-end-stage renal disease patients and families. Basic Healthy Start is directed towards educating those patients with mild chronic renal impairment on how to manage the disease process and how to maintain renal function. Advanced Healthy Start is a more intensive one-on-one session of at least 1 hour each with the dietitian, social worker, and nurse. The nurse assesses learning style and special learning needs; reviews physiology of the kidneys; provides instructions on treatment modalities; educates patients regarding their own medications and medication adherence; and reviews patient's laboratory values. The dietitian develops and instructs the patient on an

individualized diet prescription and meal planning. The social worker provides an in-depth assessment of financial and psychosocial needs, as well as assistance to the patient in choice of treatment.

Maine

The National Kidney Foundation of Maine

P.O. Box 1134 630 Congress Street Portland, ME 04104

Phone: (800) 639-7220 or (207) 772-7270

Fax: (207) 772-4202

Email: <u>ksbnkfm@maine.rr.com</u>
Website: http://www.kidneyme.org

Karen Burrell, Director of Patient Services and Programs

The National Kidney Foundation of Maine participates in the KEEP (Kidney Early Evaluation Program) program and also conducts an annual symposium for medical professionals each September.

Massachusetts

The National Kidney Foundation of Massachusetts, Rhode Island, New Hampshire, and Vermont

129 Morgan Drive Norwood, MA 02062

Phone: (800) 542-4001 or (781) 278-0222 Website: http://www.kidneyhealth.org Tracey Thompson, Executive Director

Sandie Guerra Dean, LICSW, Regional Director of Patient Services

The National Kidney Foundation of Massachusetts, Rhode Island, New Hampshire, and Vermont offers a number of KEEP (Kidney Early Evaluation Program) screenings throughout the four-State region. These are done in collaboration with church programs, the NAACP, Hispanic organizations, and other health care organizations that promote education and early intervention in high-risk populations. They participate in public health screenings in corporations that employ diverse ethnic and racial populations. They recently participated in a health screening program sponsored by the American Diabetes Association that attracted over 3,500 participants.

In May 2002, in conjunction with several major health insurers in the area, they offered a professional education program targeting primary care physicians. The program is titled "Management of Chronic Kidney Disease — Partnership Between Primary Care and

Nephrology." The goal of this program is to inform primary care physicians of the new chronic kidney disease guidelines and the importance of early detection and intervention.

The Patient Services staff provide literature and information to individuals who call the office with questions regarding kidney disease and risk factors.

In conjunction with the New England Chapter of the Polycystic Kidney Disease (PKD) Research Foundation, they offer an annual educational program for those affected or at risk for developing PKD. Topics include nutrition, information on research, treatment options, legislative activities, etc.

Michigan

The National Kidney Foundation of Michigan

The Port Authority 8109 East Jefferson Detroit, MI 48214 Phone: (313) 331-2800

Fax: (313) 331-9294

Website: http://www.nkfm.org

The National Kidney Foundation of Michigan has a program called "Healthy Hair Starts with a Healthy Body." They trained 80 stylists to give educational and prevention health chats to their clients while their hair is getting done. They have reached more than 2500 African-American women with information about hypertension, diabetes, kidney disease, and nutrition. They encourage their clients to go to the doctor if they are at risk. They also collect evaluation data—49 percent of 440 clients had started a new prevention behavior 1 month after the health chat, 49 percent discussed their risk with or saw a doctor, and 73 percent took a preventive step or saw a physician. Six women were diagnosed with diabetes or hypertension. In follow-up phone calls, 93 percent of those who had adopted a new healthy behavior such as a low-salt diet or walking were still practicing that behavior. The National Kidney Foundation of Michigan also runs the KEEP (Kidney Early Evaluation Program) program.

Mississippi

The National Kidney Foundation of Mississippi

P.O. Box 55802 Jackson, MS 39296 Phone: (601) 981-3611 Fax: (601) 981-3612

Email: lmooty@yahoo.com

Website: http://www.kidneyms.org
Gail Sweat, Executive Director

Lynda Mooty, Director of Patient Services

The National Kidney Foundation of Mississippi participates in KEEP (Kidney Early Evaluation Program). They send out press releases from time to time warning people who are at risk to see a doctor and request a BUN or creatinine test. A newscaster, Marsha Thompson, does a piece on the news each day called "Medical Matters," and they use her spot to promote kidney disease prevention messages.

Missouri

Missouri Kidney Program

AP Green Building, Suite 111 Columbia, MO 65211-8180

Phone: (800) 733-7345 or (573) 882-2506

Fax: 573-882-0167

Email: mokp@health.missouri.edu

Website: http://www.hsc.missouri.edu/~mokp or www.muhealth.org/~mokp

The Patient Education Program of the **Missouri Kidney Program's Center for Renal Education** began in 1983 as a cost-containment grant, with the hypothesis that if a patient was educated about dialysis treatment options prior to the need for dialysis, the individual would be more likely to select a less costly form of treatment (i.e., home dialysis or transplantation). While the program encourages patient participation prior to beginning dialysis, those who already have begun treatment also are encouraged to attend. The professional education component of the Center for Renal Education is designed to provide accredited continuing education programs for Missouri end-stage renal disease facility staff while avoiding the expense of long-distance travel.

Nebraska

The National Kidney Foundation of Nebraska

7101 Newport Avenue, Suite 301

Omaha, NE 68152-2116

Phone: (800) 642-1255 or (402) 572-3180

Fax: (402) 572-3211 Email: ceo@kidneyne.org

Website: http://www.kidneyne.org
Tim Neal, Chief Executive Officer

The National Kidney Foundation of Nebraska runs a Joint Council Workshop that provides a seminar for Health Care Professionals covering the "hot topics" relevant to their care of patients with chronic kidney disease. The workshops take place annually in September and addresses topics such as treatment and coping for patients. They also participate in the KEEP (Kidney Early Evaluation Program) program.

New Hampshire

See National Kidney Foundation of Massachusetts, Rhode Island, New Hampshire, and Vermont under Massachusetts.

New York

The National Kidney Foundation of Central New York

731 James Street Suite 200 Syracuse, NY 13203

Phone: (877) 8-KIDNEY or (315) 476-0311

Fax: 315 476-3707

Email: NKF@CNYKidney.org

Website: http://128.121.207.181/NKF/main.asp

Marion Makhuli, Executive Director

The National Kidney Foundation of Central New York (NKF of CNY) is currently offering KEEP (Kidney Early Evaluation Program) two to three times a month, targeting African Americans, Native Americans, and Hispanics. They are assisted in their outreach efforts by ministers of African-American and Hispanic churches. Their Syracuse Community Heath Center partner is working with the Native American population to provide KEEP, in conjunction with the NKF of CNY. These efforts are partially supported by a grant from the U.S. Department of Health and Human Services, Office of Minority Health.

The importance of physician education regarding management of early signs of kidney disease is recognized by the NKF of CNY. The KEEP Medical Director presents the KEEP screening outcomes and the Kidney Disease Outcomes Quality Initiative (K/DOQI) clinical practice guidelines at State University of New York Upstate Medical University Hospital, for the Department of Nephrology, Family Practice Groups, and their Nurse Practitioners. An informative letter about treatment guidelines is sent to each KEEP participant's physician.

At community health and State fairs, volunteers staff booths offering blood pressure screening and presenting information concerning the prevention and treatment of kidney disease. Organ donor cards are also available.

The National Kidney Foundation of Upstate New York

3300 Monroe Avenue, Suite 100D

Rochester, NY 14618

Phone: (800) 724-9421 or (585) 264-0420

Fax: (585) 264-0109

Email: adw4nkf@rochester.rr.com Website: http://www.kidneynyup.org

Abby Weaver

The National Kidney Foundation of Upstate New York (NKF–UPNY) is beginning a series of radio spots called Medical Minutes that will air on the locally owned African-American radio station. A physician from the African-American community will record 60-second spots. The radio station has given a discounted rate, and NKF-UPNY is applying for grants to increase the number of spots and to add billboards. The topics will include high blood pressure, diabetes, and kidney disease awareness; ways to reduce your risk; and behaviors to change. Ad space has also been donated monthly in the local Southwest Area News (African-American-owned newspaper) to raise awareness about high blood pressure, diabetes, and kidney disease.

National Kidney Foundation of Western New York

3871 Harlem Road, Suite 11

Buffalo, NY 14215 Phone: (716) 835-1323 Fax: (716) 835-2281

Email: nkfofwny@hotmail.com
Website: http://www.nkfofwny.org
Vickie Keidel, Executive Director
Kim Tatoian, Director of Special Events

The National Kidney Foundation of Western New York held a symposium on chronic kidney disease in April 2002. Topics covered included the new National Kidney Foundation K/DOQI (Kidney Disease Outcomes Quality Initiative) guidelines, anemia and cardiovascular disease in chronic kidney disease, and prevention and therapy of renal bone disease.

Ohio

The National Kidney Foundation of Ohio

1373 Grandview Avenue, Suite 200

Columbus, OH 43212-2804 Phone: (614) 481-4030 Fax: (614) 481-4038 Email: nkfohio@core.com

Website: http://www.nkfofohio.org
Orelle Jackson, Executive Director

The National Kidney Foundation of Ohio (NKF of Ohio) has the following educational components for public and professional education:

• **Renal Conference**. Each spring, the NKF of Ohio provides a certified 2-day conference for health care professionals and those planning a career working with individuals with kidney disease. The purpose of the conference is to provide quality education and updates for nurses, registered dietitians, social workers, and dialysis technicians who work with individuals with kidney problems or in health care fields such as dialysis, transplantation, or organ donation.

• Community Outreach. NKF of Ohio conducts annual public education campaigns that focus on kidney disease and prevention and include messages about healthy eating, the warning signs of kidney disease, and the importance of early intervention. In addition, the NKF of Ohio has over 100 educational materials discussing the kidneys, kidney disease, early intervention and prevention, treatment options, nutrition, rehabilitation, health care services, organ donation and transplantation, and donor family support. Kidney Comments is a quarterly newsletter for individuals with kidney disease, families, health care professionals, donors, legislators, and other interested individuals. Display boards, educational materials, and speakers are available for schools, companies, civic groups, health fairs, and the community.

The African American Health Education Program of the Kidney Foundation of Greater Cincinnati

220 Victory Parkway, Suite 510

Cincinnati, OH 45206 Phone: (513) 961-8105 Fax: (513) 961-8120

Website: http://home.fuse.net/kidney/programs.htm

The African American Health Education Program of the Kidney Foundation of Greater Cincinnati was specially designed for adults and children in the African-American community at risk for kidney disease, particularly those who have, or who are at risk of having, high blood pressure or diabetes. The mission of the program is to prevent or slow the onset of kidney disease within the African-American community through ministry, education, and counseling. The programs and activities offered through this program include workshops, speakers, discussion groups, seminars, educational materials, and a newsletter. Topics may include information about diabetes, high blood pressure, medications, diet, kidney disease, transplantation, dialysis, and other related health care topics.

Oklahoma

The National Kidney Foundation of Oklahoma

3617 NW 58th, Suite 101 Oklahoma City, OK 73112

Phone: (800) 946-6405 or (405) 947-6405

Email: MKFO@aol.com
Website: http://www.nkfo.org

The National Kidney Foundation of Oklahoma sponsored a conference on Diabetes for American Indians that stimulated an interest among various tribes that together formed the American Indian Kidney Conference. The first conference included exhibits, a gospel sing, and a pow-wow, and led to three KEEP (Kidney Early Evaluation Program) screenings among the tribes. The second conference was called, "Triple Threat: Diabetes, Hypertension, and Kidney Disease." It included information about the prevention, detection, and treatment of all three diseases.

Pennsylvania

The National Kidney Foundation of Western Pennsylvania

555 Grant Street

(Omni William Penn Hotel), Suite 380

Pittsburgh, PA 15219

Phone: (800) 261-4115 or (412) 261-4115

Fax: (415) 261-1405

Website: http://www.kidneywp.org

The National Kidney Foundation of Western Pennsylvania has an African American Outreach Education Program (AAOEP). Carol Burns, the Program Coordinator, serves as a direct liaison to a 22-member volunteer AAOEP committee. The primary goals of the AAOEP are to:

- Reduce the high incidence of end-stage renal disease among African Americans through community education and empowerment; and
- Encourage African Americans to become organ tissue donors.

The National Kidney Foundation of Western Pennsylvania has embarked on an aggressive initiative to educate members of the minority communities about the importance of prevention, early detection, and treatment. Staff have held several community health awareness programs at African-American churches and participated in many neighborhood "Community Day" programs, college and university health fairs, other health programs, and conferences throughout the Western Pennsylvania area. The staff continue to collaborate with other community organizations and agencies.

Rhode Island

See National Kidney Foundation of Massachusetts, Rhode Island, New Hampshire, and Vermont under Massachusetts.

South Carolina

The National Kidney Foundation of South Carolina (NKSFC)

5000 Thurmond Mall, Suite 106

Columbia, SC 29201

Phone: (800) 488-2277 or (803) 799-3870

Email: <u>info@kidney-sc.org</u>

Website: http://www.kidney-sc.org

The National Kidney Foundation of South Carolina Making Lives Better Public Education Program has the following components:

- **KEEP** (Kidney Early Evaluation Program).
- **Kidneys In The Classroom School Education Program.** This is a program designed to give elementary school students (grades 3-5) a better understanding of kidney disease and its treatments, and to increase awareness of the importance of organ donation and transplantation. This interactive program also gives the students the opportunity to meet and ask questions of a kidney transplant recipient.
- March Is Kidney Month. A campaign with the purpose of increasing public awareness of kidney and urinary diseases, the role of the kidneys in maintaining overall good health, and the importance of early intervention in preventing kidney disease.
- **Health Fairs.** The National Kidney Foundation of South Carolina participates in health fairs around the State, distributing information to thousands of South Carolinians.
- Speaker's Bureau.
- **Educational Materials.** Information on kidney and urinary tract diseases and organ transplantation are available on request.

Texas

National Kidney Foundation of Southeast Texas

2400 Augusta, Suite 252 Houston. TX 77057

Phone: (800) 961-5683 or (713) 952-5499

Fax: (713) 952-5497

Email: customerservice@nkfset.org

Website: http://nkfset.org

Program Descriptions: The **National Kidney Foundation of Southeast Texas** sponsors a Professional Symposium for physicians, dietitians, nurses, and social workers that draws over 250 participants each year and serves as an educational opportunity for medical professionals from all across the State of Texas to gather the latest news from leading chronic kidney disease (CKD) researchers. Continuing education units (CEUs) are provided for attendance at this event. More information on the most recent symposium, held March 8, 2002, is available at http://www.texaskidney.org.

An all-day free patient symposium in both English and Spanish for newly diagnosed CKD patients and their families is provided each year. Speakers are brought in to address relevant subjects such as how to cope with a disabling illness, sexual issues, and pain management.

For the past 17 years, the National Kidney Foundation of Southeast Texas has been sponsoring Camp Shining Stars, an annual summer camp for children suffering with CKD. Camp Shining Stars is a unique camp experience developed by the National Kidney Foundation of Southeast Texas and staffed by trained medical personnel from Memorial Hermann Children's Hospital and the University of Texas Medical Branch at Galveston. Camp Shining Stars offers children

with CKD a weeklong escape from the watchful care of their parents to enjoy the wonders of canoeing, horseback riding, fishing, arts and crafts, and many other exciting activities. Children suffering from CKD typically spend 3 to 4 hours a day intravenously connected to a dialysis machine for 3 to 4 days a week. These painful and time-consuming treatments make it nearly impossible for kidney patients to attend regular summer camps. In an effort to provide an exciting, supportive, safe, and healthy camp experience for children with kidney disease to explore, discover, and grow, the National Kidney Foundation of Southeast Texas created Camp Shining Stars. Recognizing that camp is best enjoyed with a buddy, the National Kidney Foundation of Southeast Texas allows each patient to bring one sibling or friend with them to the camp. Camp Shining Stars, which is held at the Camp for All Campgrounds in Burton, Texas, is one of only six camps of its type in the United States that services the needs of children with CKD. Last year, children from all over the State of Texas and Louisiana came to Camp Shining Stars for a week of fun and friendship. The high cost of caring for a child with CKD makes it nearly impossible for most parents to afford to pay the camp fees for their children to attend Camp Shining Stars, so the National Kidney Foundation of Southeast Texas provides scholarships to those who demonstrate a need.

Vermont

See National Kidney Foundation of Massachusetts, Rhode Island, New Hampshire, and Vermont under Massachusetts.

Washington, D.C.

National Kidney Foundation of the National Capital Area

5335 Wisconsin Avenue, NW, Suite 300

Washington, DC 20015 Phone: (202) 244-7900 Fax: (202) 244-7405

Email: mhonohan@kidneywdc.org
Website: http://www.kidneywdc.org

Melissa Honohan, MA - Director of Medical and Community Programs

Project Prevention is a comprehensive, preventive health screening and education program developed by the National Kidney Foundation of the National Capital Area to identify individuals at risk for kidney disease. The program takes place in various settings including, local churches, senior centers, community health fairs, hospitals, corporate offices, and government facilities. Project Prevention screenings include:

- Pre-screening health history questionnaire
- Blood pressure measurement to screen for hypertension
- Fingerstick glucose measurement to screen for diabetes
- Urine test to screen for blood or protein in the urine

- On-on-one consultation with a physician or registered nurse to discuss results, risk factors, follow-up care, and lifestyle changes
- Professional staff, flyers and posters for in-house distribution, educational materials for participants, and follow-up for those with abnormal results